THE NINE DOMAINS OF FAMILY QUALITY OF LIFE: ADULT CHILDREN WITH INTELLECTUAL DISABILITIES

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Abstract

Introduction: Young people with moderate and severe intellectual disability (ID) who are older than 21 years are not included in any formal way in education and rehabilitation programs, except in scattered and modest activities sponsored by parents´ associations. The goal of this study is to provide initial data on quality of life for families with adult children who have ID in the Canton of Sarajevo in Bosnia and Herzegovina (B&H).

Participants, Materials/Methods: The sample consisted of the main caregivers in 35 families that have adult children 18 years and over with ID who attended classes in a specially adapted program in a Centre for children with ID, autism and cerebral palsy (n = 16), and in the Vocational Secondary School in Sarajevo, (B&H) (n = 19). Regarding diagnosis as reported by the main caregivers, 15 sons and daughters had ID of unknown etiology, eight had cerebral palsy, four had Down syndrome, four had epilepsy and another three had epilepsy as co-morbidity, two had autism and two had Prader-Willy syndrome. One had dual diagnosis (ID and mental illness). The principle measure used for family quality of life in the study was Family Quality of Life Survey 2006 – main caregivers of people with intellectual or developmental disabilities (FQOLS-2006). The 9 domains of FQOLS Survey address specific areas of family life: health, financial well-being, family relationships, support from others, support from services, influence of values, careers, leisure and recreation, and community integration. The mean scores and standard deviations of the six measurement dimensions (Importance, Opportunities, Initiative, Attainment, Stability and Satisfaction) for the nine domains are shown in the Study.

Results: The nine domains measured by the scale were all rated high for Importance. Opportunities were considered to be particularly low for Financial Well-Being and Support from Others. Attainment is rated low for these two domains, and this appears to explain their low Satisfaction scores. Attainment and Satisfaction scores for Support from Services were lower than Opportunities and Initiative scores. This suggests that, while services appear to be available, they may not be the ones that families consider they want or need.

Conclusions: The goals of education and rehabilitation in B&H, similar to most other countries of the world, are to work towards community inclusion, acceptance of diversity, optimal physical and mental health, and personal and social well-being.